

...offering  
**information &  
inspiration**  
to individuals with  
disabilities and  
their families  
as they direct their  
own supports and  
services



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## 'It has always been the right thing to do'

A provider's perspective on Real Life Choices

Cape May County is one of the last rural gems left in New Jersey. Largely a farming community with a thriving tourism economy, it has a population of just over 100,000 people. According to Frank Uncle, the Executive Director of the Arc of Cape May, "It's a great place to live and work." But it is also a hard place to hire direct support staff.

*"...Real Life Choices fits the Arc of Cape May perfectly. Our posture has always been, "tell us what you want and we will try to do it for you."*

*- Frank Uncle  
Executive Director,  
The Arc of Cape May County*

"We have been doing Real Life Choices (RLC) for a year and our biggest challenge has been finding staff," says Uncle. At \$10.20 an hour, Uncle admits it is hard to compete with the tourism industry to recruit personnel. "People can make good money at a restaurant, often with better hours."

To solve the problem, Frank Uncle has gotten creative. "We offer a lot of flexibility for our staff. They can work 2 hours a week or we can weld together a full time schedule, depending on what the person wants. We are able to pay 75% of family health benefits for our full time staff which can make a big difference. And some of our employees bring their own kids with them to the job. The parents in the program are thrilled, and the typical kids develop greater sensitivity and a heightened awareness to disability. It's good for everyone!"

For years, The Arc of Cape May has seen the need for more wrap around services like those available through Real Life Choices. Uncle recalls three or four occasions in the past when parents of adults with developmental disabilities on the waiting list would bring their son or daughter for a weekend to The Arc's Crisis Respite home and simply not come back for them. "They just couldn't do it anymore," says Uncle. "They couldn't keep waiting for help."

Uncle thinks RLC can help avert these situations by supporting families *before* they reach the breaking point. "Philosophically, Real Life Choices

## **The Right Thing to Do**

*continued from the cover*

is the way to go,” says Uncle. “Now that families have funding, *they* tell us what they need.”

But The Arc of Cape May has already found that the demand for services exceeds their capacity to meet it. “There are some people who call for help and we can do a lot for them. There are others who we cannot help,” admits Uncle. “People get mad because they are not getting what they need, but we are a non-profit agency. Our contracts don’t cover all our costs,” Uncle concedes. “We rely on donations and United Way dollars – we are not an entitlement like the school system. We do what we can with the resources we have.”

Uncle acknowledges funding barriers inherent in the system. “People have to depend on their budget from the Division of Developmental Disabilities (DDD) to determine the services they get. We have had people ask us for more than what they were allocated. They probably need it, but without funding, we simply cannot do it.”

Another challenge for provider agencies, according to Uncle, are the reimbursement rates established by DDD. “From the beginning, many providers felt the rates were not adequate,” said Uncle. “Our actual costs are closer to \$20.00 an hour when you include recruitment and training, quality assurance, and back-up coverage if there is an emergency or someone is out sick.”

According to Uncle, “Being a provider through RLC has been a bumpy ride but it’s the right thing to do. It is what families want.”

In spite of its role as a service provider, Uncle views the Arc of Cape May primarily as an advocacy organization, with deep roots in its all-volunteer history. “We have not had any conflicts with DDD with the RLC plans, but if families had trouble, we would help. We are good at helping people get what they need.”

Uncle sees RLC as *part* of the system, not the whole system. “I think we will always need other options and residential services,” says Uncle. “I still have moms call me up and say ‘save a spot at the group home for my son’. Real Life Choices helps these parents NOW, but they will need more services at some point.”

## **Changes To SSI May Increase Benefits and Ease Eligibility**

*by Herbert Hinkle & Valerie Powers Smith*

Important changes went into effect earlier this year affecting eligibility and benefits under Supplemental Security Income (SSI).

To be eligible for SSI, applicants must meet an income and resource test. “Clothing” has now been eliminated from the definition of income. This means that payments for clothing or in-kind gifts of clothing will no longer be counted as income.

What is the practical effect of this change? SSI recipients living at home with parents frequently have their benefits reduced by 1/3 (from roughly \$600 per month to \$400 per month) because of in-kind contributions by parents of food, clothing and shelter. Now that clothing has been eliminated from the definition of income, more people should qualify for full benefits.

The regulations also change the definition of a resource. An automobile owned by an SSI recipient is no longer counted. Likewise, personal possessions, regardless of value, are no longer counted.

Special needs trusts are still needed to hold assets which a parents wants to leave someday to a disabled child. The new rules do not change the need for this, but they do make things a little easier for applicants.

*Herbert Hinkle and Valerie Powers Smith are with Hinkle & Fingles, Attorneys at Law. They have offices in New Jersey in Lawrenceville, Marlton, and Florham Park, and in Pennsylvania in Yardley and Plymouth Meeting. They lecture and write on topics of law and disability, and are available to speak to groups at no charge.*

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# Career Opportunities & Resources

## CAREER OPPORTUNITIES

### Morris County Area:

**Personals Assistant:** F/T, P/T Whippany area. One or two positions available; flexible hours. Daytime, week day hours, with some weekend hours. P/T Weekend hours also available. *Contact Neeta Das 908-689-7228*

**Live-In Position:** F/T, Madison area. Own room, shared bath. *Contact Neeta Das 908-689-7228*

### Essex County Area:

**Home Support:** P/T, hours flexible. Montclair area  
*Contact Neeta Das 908-689-7228*

### Bergen/Passaic County Area:

**House Mate:** Wayne. Woman wanted to share apartment with woman in her early thirties (who happens to use a wheelchair, and has a team of assistants). Available Immediately. Primary Responsibility: Be there during the week at night from approximately 10pm to 6am (flexible) in case of overnight emergencies (fire, sudden illness, etc.) May have to assist (minimally) in evening and morning transfer from bed to wheelchair.

Private bedroom, share bath/kitchen. Quiet area within walking distance to shopping, transportation, varied worship houses, library, and municipal complex. Close to area highways (Rt.'s 23, 46, 80, & 287). Tennis courts (and pool in future). *Contact Sarah at 973-633-9495 or Patrick at 973-956-9410.*

## RESOURCES

### **Freecycle**

On the premise that one man's (or woman's) trash is another's treasure, the concept of freecycle was born. Freecycle links up people looking to give away something FOR FREE. to people who want something, FOR FREE. Its like e-Bay, only its FREE-bay.

The members-only forum is for anyone who's trying to offer something, find something, or simply help out the environment and the local community. There are groups throughout New Jersey.

Instead of filling the landfills, why not connect to someone who wants what you have! Or, instead of buying something new, see what someone else has to GIVE AWAY FREE. You can find anything, from CDs to computers, furniture to boxes!

As a member, you can post your requests, post your wants, and connect to someone in your community. Whether you are giving away your old stuff or gaining a brand new item for yourself, you are reducing the amount of waste we are producing!

Check out [www.freecycle.org](http://www.freecycle.org) for more about this growing movement.

### PLEASE ADD ME TO THE MAILING LIST:

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July/August 2005

**new**  **directions**

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## Medicaid Institutional Bias Legislation Introduced

On July 29, Senators Charles Grassley (R-IA) and Evan Bayh (D-IN) introduced the bipartisan *Improving Long Term Care Choice Act*. This legislation gives states the option of creating home and community based services and supports within the State Medicaid plan, without obtaining a waiver. States would also be permitted to allow individuals to choose to self-direct services.

Medicaid is the most valuable public resource for children and adults with disabilities to access health and long-term supports and services in the community. It serves nearly 11 million people with disabilities, of whom 7 million are under age 65.

Under this new option, states must establish a more stringent eligibility standard for placement of individuals in institutions than for placement in a home and community-based setting. The bill also provides tax credits for long term care, educates consumers and provides protections for long term care insurance and removes barriers to integrated acute and long-term care services for dually eligible individuals. Many in the disability community have been working for years for this kind of positive reform of the institutional bias in Medicaid. The legislation and a summary of the bill, are on the Association of University Centers on Disability's website at [www.aucd.org/aucd\\_medicaid](http://www.aucd.org/aucd_medicaid)

**new**  **directions**

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